

21st September 2019

To Whom it May Concern

My 8 year old son is allergic to wheat, egg, dairy, peanut, cashew, pistachio, gluten, kiwi fruit and banana.

He has had an anaphylactic reaction when he was in Kinder when given the wrong food to eat. Thanks to an ambulance who was in the area getting him to hospital saved his life.

After that episode we signed forms to bring our own food into kinder and after moving did the same thing at the new centre. Each day still brought anxiety around the preparation of his meals and we worked out risk management plans with each centre on how to keep him safe.

School as brought more challenges in awareness around his multiple allergies, including asthma, hay fever and eczema. Although risk management plans have been written and discussed near misses have happened with reactions being contained with antihistamine. This is due to our son knowing never to eat anything we have not given him. Living with this daily fear that our son may have an anaphylactic reaction to something that we have not been able to prepare for or prevent is an ever present anxiety of massive proportions.

The fact that there are treatments such as oral immunotherapy available in the USA that are changing childrens & families lives is amazing. Why are we unable to have this treatment in Australia? Why can't we protect our children and change their quality of life?

He never eats out, he never gets anything from the canteen at school, he never eats anything at a party or at a friends house. This may not sound like much but food and eating is a constant, we can't choose not to do it, it is always there and it can kill my son. A slice of bread and he could die, an egg is death, a glass of milk he stops breathing, a peanut butter biscuit and I wouldn't read him another bedtime story a cashew or pistachio chocolate I would never get to hold him in my arms again. Dramatic yes, reality YES.

All these things are enjoyable daily parts of the majority of people's lives, but for a lot of families like mine are a minefield of stress and anxiety. This worry is hard not to transfer to a child, but the option of him accepting a biscuit from a friend and dying is not one we can risk. So you try to equip your child as best you can with the knowledge to keep himself alive. The older they get the more they put 2 and 2 together. How can this not impact on a child, why isn't this part of a plan to assist us in supporting our beautiful, innocent children? Again why isn't there options of treatments that can give us hope that they can live full and free lives?

Access to treatments, access to specialised mental health support that families can actually afford, or even better be part of NDIS, educating schools in the seriousness of allergies, inclusiveness of catering with transparency into the kitchen practices. Hospitals not feeding children with allergies until AFTER speaking with parents ensuring food is safe for them. Awareness of the costs of alternative foods. Serious consequences for food companies when additional ingredients are found in their products other than what is on the label. Medications having ingredients labeled. A national standard for all food & medication labeling, why should we be researching to find out what is in something? Or what something means on a label?

I need to advocate for my son where I can, I don't know how to express the utmost importance for options for these health issues. There is so little known about the 'why' & 'how' of it all. But we have hope in treatments, proven in the oral immunotheray in the USA. Please allow this in Australia, the children and families (and adults of course) living with this life threatening issue rely on some common sense choices. It's proven to work, lets get it here NOW.

Help us keep our children safe and give them the chance to live a normal life. The life that most people take for granted, as in, eating without worrying about if the food they are about to put into their mouth could kill them.

Regards
Nikki Brown